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Emotional harm following incidents in health care: What can researchers do?

The harm that patients experience following incidents has to date been confidently described by researchers as “unintended physical injury resulting from or contributed to by medical care that requires additional monitoring, treatment or hospitalisation, or that results in death”¹. Without referring to the patients concerned, the harm categorisations that have to date been proposed distinguish levels of harm severity (severe harm, moderate harm and low harm) and types of harm (unintended harm; avoidable harm; unnecessary harm). Using these self-referential distinctions, a UK House of Commons Public Administration Select Committee signed off on a 2015 report into clinical incidents in the NHS stating that 1.4 million incidents occur “[p]er year, of which 1.3 million are ‘low harm’ or ‘no harm’.” The report continues: “Of the total, 1,421 deaths were reported following incidents, 49,000 resulted in moderate harm; 4,500 resulted in severe harm”².

This approach to describing harm reappears in a recent editorial whose title offers hope (‘Accounting for harms that cannot be counted’³), but whose contents offer little redress. Framing non-countable harms as ‘non-rate-based harms’, the piece states: “These non-rate-based harms can be identified by examining a variety of data sources. Some are identified through reporting systems, some by direct observation, some from reports to risk management, some during review of the medical record, and some through claims data. To make sense, some non-rate-based harms are also identified through staff surveys, such as when our organization measures safety culture, we ask staff how the next patient might be harmed.”³ What none of the data sources just listed will illuminate however is what healthcare-caused harm means to patients,⁴ and how the complex consequences of such harm *for patients and families* are to be understood and tackled.⁵

A report included in this issue titled ‘A Multi-Stakeholder Consensus-Driven Research Agenda for Better Understanding and Supporting the Emotional Impact of Harmful Events on Patients and Families’ is among the first to ask patients and their families: what do *you* experience as harm resulting from your healthcare incident? As the report is concerned with setting out a research agenda, its first three priorities are to “establish a conceptual framework and patient-centered taxonomy of harm and healing; describe the epidemiology of emotional harm, and determine how to make emotional harm and long-term impacts visible to healthcare organisations and society at large.” These priorities are about defining, measuring, and drawing people’s attention to patients’ and families’ experiences of harm, particularly emotional harm.

The report’s fourth priority targets intervention: “to develop and implement best practices for emotional support of patients and families”. Given the ways in which harm from incidents reverberates through families and communities with one harm often cascading into more harm⁶, this last priority is paramount. It targets the well-being of patients and families for whom harm still fails to be addressed effectively and appropriately. And this is after myriad scientific studies of harm^{7 8}, inquiry reports⁹, consumer initiatives (e.g. <https://sorryworks.net>), testimonials (e.g. <https://www.patientstories.org.uk>), political activism advocating for disclosure and caring responses following incidents (e.g. <https://www.avma.org.uk>), and disclosure legislation^{10 11}. Why then is alleviating patients’ and families’ experiences of healthcare harm still so fraught?

I was recently indirectly involved in a healthcare incident. A friend lost her 54-year old male partner in 2017. The harm included death from septic shock, preceded by antibiotic anaphylaxis, swelling and rashes while the patient was in a full-body brace to support his fractured spine. The brace, left on despite the swelling and rashes, turned the patient into an inflated caricature of himself, hours before he died of septic shock. The patient, his clinicians, his partner, his children and visitors witnessed not just his rapid deterioration, but also this terrible graphic end. It left a lasting scar on the minds of all who were with him to the end.

The grief at the untimely death of this wonderful man was widespread among family and friends. The family struggled to find answers. How was the patient's cancer missed six months earlier when he was undergoing a series of tests initiated by his GP? How could they have missed his allergy? One of the children wanted to sue his hospital oncology team. They talked to me and asked for advice. If you sue, I said, it may destroy you and it is not likely to do any good. Instead, ask for a meeting, and ask what are the things that they would now do differently. Ask how they will make sure things are done differently. Ask if you can be informed in the future that things have been and are being done differently. Ask for a written report now and in a year's time. Ask for a role on the hospital's incident investigation committee or on their sepsis committee, so you can involve yourself in how the hospital deals with these kinds of cases, and you may get solace from improving the situation for future patients. They seemed relieved at my advice. It offered a positive angle on a terrible outcome.

The family were granted two meetings with the oncologist and the senior nurse. The oncologist was heard as saying, 'yes of course there are things we will do differently'. But she never committed anything about that to paper for the family. The nurse never spoke up once during the meetings, looking sternly at her lap. Neither clinician responds to the partner's last email request for further information.

The family's emotional harm put their lives, work, relationships and well-being on hold for months. Their suffering meant that I could not motivate them to ask more questions (how did the sepsis happen? what was done (and when) to tackle it? why was the brace left on when the swelling started?), let alone make demands (for a written statement, an incident investigation, an invitation to join the hospital's incident investigation committee). They were too fragile to pursue these reasoned, prodding questions and practical aims. The partner was preoccupied with taming the son's fury, guilt and blame, and perhaps therefore curbed how they all dealt with challenging issues and burning questions. The family's and friends' respect for the dead, it seemed, obliged them to respect his clinicians and not unduly criticize their actions and intentions. And so they withdrew into themselves. They celebrated the deceased's birthday, shedding more tears and talking about how much he was missed, with not much being said about his dying, the emails that were never responded to, the improvements that were never detailed.

To an outsider, it was only too clear that the patient's care, his death and the aftermath for the family had this in common: a disregard for emotion and relationship. This conclusion needs no data analysis or system solution. What it does call for is a change of heart in how we frame research, method, improvement, and harm response. A change of heart that is inspired by the insight and acknowledgement that emotion shapes and defines care both in the doing and in its undoing¹².

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